



Patients' experience of decision-making and receiving information during radiation therapy: A qualitative study



Sian K. Smith ^{a, b, *}, Django Nathan ^c, Jennifer Taylor ^d, Eleni Van Gelder ^e, Ann Dixon ^d, Georgia K.B. Halkett ^f, Christopher Milross ^g, Haryana M. Dhillon ^{d, h}

^a Prince of Wales Clinical School, Psychosocial Research Group, Faculty of Medicine, UNSW Sydney, Australia

^b Sydney School of Public Health, The University of Sydney, New South Wales, Australia

^c Sydney Medical School, The University of Sydney, New South Wales, Australia

^d Centre for Medical Psychology & Evidence-based Decision-making, School of Psychology, Faculty of Science, The University of Sydney, New South Wales, Australia

^e Faculty of Medicine, UNSW Sydney, Australia

^f Curtin University, Western Australia, Australia

^g Chris O'Brien Lifehouse, Sydney, New South Wales, Australia

^h Central Clinical School, Sydney Medical School, The University of Sydney, Australia

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ABSTRACT

Purpose: This study aimed to explore: (i) patient perceptions of how they are involved in treatment decisions about radiation therapy; (ii) patient knowledge and understanding of treatment; and (iii) what patients value in their interactions with the radiation therapy treatment team.

Method: Patients were recruited through radiation oncology departments at metropolitan hospital sites located in Sydney, New South Wales, Australia. Semi-structured interviews were conducted with 21 radiation therapy patients with different types of cancer. Data were analysed using a Framework analysis to compare and contrast patient experiences.

Results: Most patients perceived the decision to undergo radiation therapy as agreeing to radiation oncologists recommendations rather than making a choice, but they trusted their radiation oncologist and were happy to follow their advice. Only a few participants reported their radiation oncologist had explained why radiation therapy was recommended, or discussed the benefits and harms. Some participants did not feel prepared for the intensity and disruption of side effects, and conveyed uncertainty about their diagnosis and the potential risk of recurrence. Most patients, irrespective of their type of cancer, valued the treatment team showing a genuine interest in how the treatment was effecting them, and being made to feel part of the department.

Conclusion: Greater opportunities are needed to empower patients to ask questions about their uncertainties and concerns. Improvements in these areas will benefit patients and enable them to feel better prepared and know what to expect before and after their treatment.

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1. Introduction

Radiation therapy is a commonly used treatment for a range of cancer types. Approximately half of the people diagnosed with cancer should receive radiation therapy to improve local control

and life expectancy (Delaney and Barton, 2015). Radiation therapy appears to be a poorly understood treatment and often patients do not know what to expect (Long, 2001; Halkett and Kristjanson, 2007; Halkett et al., 2008). Communicating with patients in a way they can understand and addressing areas of concern helps to alleviate anxiety (Halkett et al., 2010; Thorne et al., 2013a, b; Katz et al., 2014).

Radiation therapy can be perceived as a treatment decision that is left to the radiation oncologist to decide, and information presented to patients on the benefits and harms of treatment can vary (Kuneman et al., 2015). Yet, patients who perceive they are

* Corresponding author. Psychosocial Research Group, Prince of Wales Clinical School, Lowy Cancer Research Centre C25 Level 4, UNSW, Sydney, NSW 2052, Australia.

E-mail address: sian.smith@unsw.edu.au (S.K. Smith).

involved and given balanced information report feeling less anxious and more satisfied with their care (Shabason et al., 2014; Kehl et al., 2015). Some patients, including older ones, express a desire for greater autonomy in treatment decision-making (Wang et al., 2017). Gaining an insight into how patients perceive radiation therapy decisions are made will help to identify whether options are discussed and opportunities to engage in decision-making are perceived to be made available.

There is much literature describing the information needs of people undergoing radiation therapy (Harrison et al., 1999; D'haese et al., 2000; Schäfer et al., 2002; McGuffin and J, 2004, Choi et al., 2006; Halkett et al., 2008; Halkett et al., 2010; Güleser et al., 2012; Zeguers et al., 2012; Wang et al., 2017). Collectively, most patients want comprehensive information about their diagnosis, prognosis, treatment aims and procedure, the side effects, and how to manage them. Patients also want to understand the roles of different members of the radiation therapy team, why treatment was recommended, the planning appointment and features of the procedure, such as how the machines work (Halkett et al., 2010). Patients seem to benefit from information that is staggered and tailored to their needs at particular treatment time points (D'haese et al., 2000; Halkett et al., 2010). Older women with breast cancer value receiving information about the benefits and side effects of treatment the most (Wang et al., 2017). Lacking in the literature; however, is an exploration of *how* patients with different types of cancer make sense of, and interpret the information they receive as they undergo radiation therapy, and the aspects of their treatment that they may not fully understand, requiring clarification or reiteration.

A number of studies have explored patient's experiences of radiation therapy (Gamble, 1998; Long, 2001; Halkett and Kristjanson, 2007; Halkett et al., 2008; Halkett et al., 2010; Egestad, 2013). Patients lack faith in their treatment team when they receive conflicting messages, and value being listened to and given the opportunity to ask questions (Long, 2001). Gamble (1998) found that participants valued health professionals who acknowledged their situation and displayed compassion. Patients commonly use metaphors when describing their experience of radiation therapy, and liken it to warfare as it attacks cancer (Hammick et al., 1998). Other studies have shown that radiation therapists play a key role in providing physical and emotional comfort to patients (Halkett and Kristjanson, 2007; Egestad, 2013). We note that most of this work was conducted well over a decade ago (Gamble, 1998; Hammick et al., 1998; Long, 2001), and more recent studies focus specifically on breast or head and neck cancer populations (Halkett and Kristjanson, 2007; Egestad, 2013). Given the growing movements toward patient-centered care and shared decision-making, there is a need to explore how patients with different types of cancer experience radiation therapy, and what they value in their interactions with the treatment team.

This paper presents a qualitative study conducted with people of different cancer types undergoing radiation therapy in Sydney, Australia. The study aimed to explore: (i) patient perceptions of how they are involved in treatment decisions about radiation therapy; (ii) patient knowledge and understanding of treatment; and, (iii) what patients value in their interactions with the radiation therapy treatment team. This will enable us to identify, and recommend how the patient experience in radiation therapy could be improved.

2. Methods

2.1. Methodology

A qualitative approach using semi-structured interviews was used. Phenomenology was chosen as the theoretical foundation

because of its focus on the individuals' lived experience, enabling us to explore how patients made sense of information and their interactions with treatment team (Reeves et al., 2008). Phenomenology emphasises an individual's understanding and interpretation of their experience of treatment, rather than an objective reality (Sadala MLA and RDCF, 2002).

2.2. Participants

A purposive sampling method was used to recruit adults diagnosed with different types and stages of cancer from publicly-funded outpatient radiation oncology departments at metropolitan hospital sites located in Sydney, Australia. Patients were eligible to participate if they were aged 18 years or older, were receiving radiation therapy for the first time (new diagnosis or cancer recurrence but no prior radiation therapy), and had sufficient English. Participants with a serious cognitive or psychiatric impairment were not eligible. Ethics approval was gained from the Sydney Local Health District and the University of Sydney.

2.3. Procedure

Radiation oncologists, specialising in treating different types of cancer, invited eligible patients (meeting eligibility criteria above) to take part in the study and provided them with the study information statement and a consent form. This enabled us to purposively recruit patients living with different types of cancer. Radiation oncologists or radiation oncology nurses introduced eligible and interested patients to members of the research team (DN and JT) to explain the study and obtain written informed consent. Face-to-face interviews were conducted as patients were reaching the end of their treatment to capture the overall treatment experience of initial treatment discussions, treatment planning, daily treatment and follow-up care consultations. A flexible topic guide was developed by the research team to explore patients' experiences of treatment decision-making, radiation therapy knowledge and communication with the treatment team (Table 1). Interviews were continued until data saturation was complete and no new themes found to emerge. On average, interviews lasted 25 min (range 15 to 60 min). All interviews were audio-recorded and transcribed verbatim.

2.4. Analysis

The data were analysed using 'Framework Analysis', an approach that allows themes to be explicitly considered a priori in accordance with the research questions and identified through inductive analysis (Ritchie and Lewis, 2003; Dixon-Woods, 2011). Four authors (DN, EVG, AD and SS) read the transcripts to identify themes and develop a coding index. Transcripts were coded by EVG, AD and SS and synthesised within thematic matrix charts. Mapping and interpretation involved comparing and contrasting responses across themes to identify explanations for findings.

3. Results

3.1. Sample

Twenty-one participants participated in the study, 14 males and 7 females (Table 2). The mean age was 64 years (range 44–81, SD 10.3). Seven participants had a University degree, and 17 participants spoke English as a first language. Participants had been diagnosed with a range of cancers: 5 prostate, 4 each of breast, gynaecological, and head and neck, 2 colorectal and 1 haematological and 1 melanoma.

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